

Disability and Health: Closing the Gap

Staying healthy is an elusive goal for many Americans. However, one very large group faces a dual challenge: coping successfully with a disability *and* avoiding secondary health problems that could threaten their overall well-being.

Nearly 54 million Americans—about one in five—live with some sort of mental or physical disability, including developmental conditions such as autism, muscular dystrophy, and Down’s syndrome as well as blindness, hearing loss, and spinal cord injury.

Yet, disability is not synonymous with poor health says a Montana Department of Public Health & Human Services strategy report. “Contrary to what was once a generally accepted notion, disability does not preclude being in good health. In fact, most people with disabilities have the potential to lead healthy and productive lives,” cites the report.

However, people with disabilities often do not get preventive measures designed to ward off illness or detect early stages of disease. For example, a person who uses a wheelchair may not have ready access to cancer screenings, regular dental care, or exercise programs to control weight. As a result, studies indicate that people with disability are more susceptible to chronic diseases, such as diabetes, heart disease, and emphysema.

“We have developed some very effective health care models, such as the medical home, but how extensively are these approaches being applied to people with disabilities?” asks Sharon Moffatt, chief of health promotion and disease prevention at the Association of State and Territorial Health Officials (ASTHO). “Many public health departments are trying to reach out more to people with disabilities,” adds Moffatt, “but they are encountering serious roadblocks in this era of widespread government budget cuts.”

For a snapshot of what state public health departments are doing to address the health needs of people with disabilities in this tough economic climate, ASTHO developed the 10 case studies posted on the association’s website.

“We wanted to learn more about the successes that states are having, with the hope that others can learn from their experiences,” says Ellen Schleicher Pliska, ASTHO’s Director of Family and Child Health. “And we’re particularly interested in the partnerships that are established to address such areas as chronic disease.”

A Catalyst for Change

Several of the states profiled in the ASTHO case studies operate special disability and health programs funded by the Centers for Disease Control and Prevention (CDC). Others have forged strong partnerships with other government entities, as well as university and community partners, to leverage resources, conduct essential research, and launch innovative health programs for people with disabilities.

While a very modest effort—just \$4.7 million annually for 16 states—the CDC-funded disability and health programs wield considerable influence, the case studies show. They are both raising awareness

about the health care needs of people with disabilities and are triggering new initiatives. Following are a few examples:

- North Carolina’s “Women Be Healthy” course on reproductive health for women with intellectual disabilities.
- Montana’s success with “Living Well with a Disability,” a self-care instructional module that improves health while cutting costs.
- South Carolina’s collaboration with other agencies on emergency health plans that provide for the particular needs of people with disabilities.
- New York’s site usability checklist to make health facilities more accessible, including customized examining tables and scales.
- Florida’s efforts to collect new data on overall access to care and perceptions about people with disabilities.
- California’s new tool for assessing the health of individuals moving from institutions to community settings.

“We believe that the CDC-funded disability and health network has been pivotal for providing national leadership,” says epidemiologist Jacqui Butler, acting team leader for the CDC program, which began in 1989. “It has brought attention to disability issues within public health organizations and helped build capacity for programs that improve the health and wellness of people with disabilities.”

Adds George Jesien, executive director of the Association of University Centers on Disabilities (AUCD): “These disability and health programs are very diverse, but they all serve as a focal point for expertise on disability issues.” Jesien notes that the programs fill an important role in such areas as technical assistance, data collection, policy analysis, health promotion, training and design of model programs.

Crucial Ingredient: Partnerships

To be effective, the disability and health programs must leverage their modest resources by establishing close working relationships with other government agencies, nonprofits, community organizations and universities. AUCD represents 67 University Centers for Excellence in Developmental Disabilities (UCEDDs). The centers work hand-in-hand with the CDC-funded disability and health programs and with public health at all levels.

For example, the University of Wisconsin’s Waisman Center, one of the country’s oldest UCEDDs,, offers such a wide array of research, training, and service programs in the area of disabilities that it almost serves as an “unofficial disability and health program,” says Jesien. Waisman also supports a Leadership in Neurodevelopment and Related Disability (LEND) program. LEND is a graduate-level, interdisciplinary course that has produced some of the nation’s most respected health care professionals, while encouraging strong collaborations with health departments, health care facilities, community groups, and people with disabilities and their families.

Effective collaborations, health care experts say, is a big reason why some states such as Wisconsin and Minnesota are recognized as leaders in developing innovative programs for people with disability; however they do not receive funding under the CDC disability and health program. Those states also have aggressively pushed to move health care services out of institutions and into the community.

“The focus now is to support people in their own homes with the right service at the right time,” explains Melanie Fry, a senior policy development specialist in the Disabilities Services Division of the Minnesota Department of Human Services.

But while clear gains have been made, as the ASTHO case studies show, future efforts to improve the health and well-being of people with disabilities depend to a great extent on winning the battle of the budget.

“In many cities and states, budget cuts already have begun to reverse the progress we’ve made over the last decade,” says Kelly Buckland, executive director of the National Council on Independent Living (NCIL), whose 700-plus local centers assist a broad mix of people with disabilities.” He cites reports of layoffs affecting a third of the staff at centers in New York City and Philadelphia.

A new round of grants for the CDC’s disability and health program is scheduled to be awarded in early 2012. Although interest among states is very high, Butler believes the CDC will be fortunate if it can maintain the program at its current funding.

Other advocates for people with disabilities also note the importance of key pending legislation, such as reauthorization this fall of the Combating Autism Act, which funds early screening and intervention programs for children, as well as professional training.

“I am more concerned about budget contractions than at any time in the last 20 years,” says AUCD’s Jesien, who worries about a retrenchment from the national goal of encouraging full participation in society for people with disabilities. “In this political climate, it is easier to simply stop something than get something done.”

You can learn more about programs for people with disabilities by consulting these sources:

Association of State and Territorial Health Officials (ASTHO)

<http://www.astho.org/>

CDC-Funded State Programs for People with Disabilities

<http://www.cdc.gov/ncbddd/disabilityandhealth/programs.html>

CDC Partner Organizations on Disability and Health

<http://www.cdc.gov/ncbddd/disabilityandhealth/partnerorganizations.html>

CDC Health Disparities and Inequalities Report, January 2011

http://www.cdc.gov/mmwr/preview/ind2011_su.html

CDC Grants Profile Report for 2010 (grants for all states)

http://www.cdc.gov/fundingprofiles/FundingProfilesRIA/Report_Docs/PDFDocs/Consolidated-All-States-2010-CDC-Grants-Profile-Report.pdf

National Center on Birth Defects and Developmental Disabilities (NCBDD)

<http://www.cdc.gov/maso/pdf/NCBDDDFs.pdf>

NCBDD Strategic Plan Priorities

<http://www.cdc.gov/ncbddd/AboutUs/priorities.html>

American Association of Health and Disability

<http://www.aahd.us/page.php>

Association of University Centers on Disabilities

<http://www.aucd.org/template/index.cfm>

Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

<http://www.aucd.org/template/page.cfm?id=473>

National Council on Independent Living

<http://www.ncil.org/>